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ABSTRACT

This periodical issue focuses on the theme of involvement of families in the education of their children with disabilities. It includes papers with the following titles and authors: "A Message from the Assistant Secretary: Developing Successful Partnerships between Parents and Service Providers" (Robert R. Davila); "Parent Advocacy and Children with Disabilities: A History" (Martha Ziegler); "Supporting Families: What They Want Versus What They Get" (Susan O'Connor); "A Family Responsive Approach To the Development of the Individualized Family Service Plan" (Ann P. Turnbull and others); "Project Vision: Outreach to Infants in Rural Settings" (Jennifer Olson); "Angles of Influence: Relationships among Families, Professionals, and Adults with Severe Disabilities" (Philip M. Ferguson and others); "Training Part H Early Intervention Practitioners To Work Effectively with Families" (Carl J. Dunst and Angela G. Deal); "Implementing Individualized Family Service Planning in Urban, Culturally Diverse Early Intervention Settings" (Lisbeth J. Vincent); "Parents: The Critical Team Members" (Patty McGill Smith); and "Serving Minority Children Who Are Severely Emotionally Disturbed and Their Families: The Need for Culturally Competent Systems of Care" (Marva P. Benjamin). (JDD)

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A Message from the Assistant Secretary

Robert R. Davila, Ph.D.

Developing Successful Partnerships Between Parents and Service Providers

From the remarks I hear from parents all across the country, I am struck by the fact that all parents want the same thing for their children: a quality education. Since the enactment of the Education of the Handicapped Act in 1975, retitled the Individuals with Disabilities Education Act in 1990, expectations for a quality education by parents of children with disabilities have steadily risen. Now all parents, including parents of children with disabilities, have high expectations of what our educational system can and should do for their children. All parents, including parents of children with disabilities, want to know that their children are being prepared for a full, productive, independent life as participants in their communities. The value of family involvement has long been recognized in special education, and at the Office of Special Education and Rehabilitative Services (OSERS), we continue to support programs for families of children with disabilities. We continue to be committed to parental empowerment and to maintaining a strong role for parents in President Bush's AMERICA 2000 education reform movement.

Family involvement is crucial to the success of OSERS' programs, and parents' activities as advocates and providers of information and services are key to the success of this involvement. We must make the most of the strengths and bonds that occur between family members because we cannot afford to pass up any opportunity that will help each child to develop to his or her full potential. And above all else, we need to develop successful working partnerships between the family and professional service providers. It is through the establishment of such productive relationships that great things can be accomplished. If we are to offer coordinated services to individuals with disabilities from birth through adulthood, sound working relationships between the family and professionals are essential.

I know that there are many times when parents and professionals see themselves on different sides of a fence. And yet, once we realize that we are all working for the same goals—that we are all working for the best interests of the children we serve—then the fence disappears. We all know that an adversarial position on either side will hinder accomplishments that are enhanced by an attitude of collaboration.

The Congress recognized two important things in 1986: the need for services for very young children with disabilities and their families, and the need for partnerships between parents and service providers in order to make those services available. Partnerships are an integral part of Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, which established the early intervention program for infants and toddlers, what we call Part H. In passing this law, Congress acknowledged that even at birth, the adoption of a coordinated service delivery system is critical.

And as students with disabilities move through and beyond the school system, the need for effective partnerships does not diminish. One striking example of how this continuing need is addressed is in the new and exciting provisions of the IDEA that are specifically concerned with the delivery of transition-related services. The Congress, in recognizing the vocational rehabilitation system as playing a key role in the successful transition of youth with disabilities into adult and community life, has authorized a new competitive state grant program in the area of transition. The Secretary of Education is directed to make one-time, five year competitive grants for joint state education agency and vocational rehabilitation agency projects to implement and improve transition services for youth with disabilities from age 14 until they leave school. These grants will assist states in developing cooperative agreements, interagency working relationships, and other mechanisms to ensure long-lasting positive transition outcomes. I have been especially impressed by the role parents play in working with these public agencies to make the right decisions for their children.

It is always a challenge to be a parent. We must constantly weigh what we desire for our children against what we can reasonably expect from an imperfect system. We constantly have to adapt our parental role as our children grow, knowing that there will often be a disparity between what we can give

Continued on back cover

Family Involvement

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Parent Advocacy and Children with Disabilities: *A History*

Martha Ziegler, Director

Technical Assistance for Parent Programs (TAPP)

In 1967, Mary Ann, my daughter with autism, was four years old; it was time to think about school for her. When I called the local school district I was told, "We are tentatively planning to start a program for children with mental retardation next year. We have not thought about autistic children yet." And this response was legal!

That was before Section 504, before P.L. 94–142, yet less than a quarter of a century ago. A year later, after our family moved to another state, Mary Ann was "allowed" to attend a private school, 20 miles from home, with tuition partly paid by the state, partly paid by the family, and partly paid by continuous fundraising by parents. There was no involvement of the local school system in her program.

After a second family move, in 1971, we insisted that Mary Ann go to public school. But the separate class she attended, in the basement of an elementary school, was dismissed an hour early each day. I was puzzled by that custom, but her autism was so mysterious, I thought maybe there was a good reason. After a few mornings when I

Photo by David Warren

received a phone call from Mary Ann's teacher saying, "Come get Mary Ann—she does not want to learn today," I figured out that these shortened hours had nothing to do with Mary Ann, that it was the convenience of the teachers that mattered.

My son's teachers and principal would not have dared do such a thing, but there were very few rules governing Mary Ann's education. It was still a privilege, not a right, for her to go to school at all.

Around that time I became acquainted with a parent in another town who had a daughter with cerebral palsy. This mother was thrilled that after several years of trying, she had finally succeeded in having her daughter attend public school, in regular class with her same age peers. The mother was so grateful that she continued to drive her daughter to and from school each day. It did not occur to her that her daughter might have a right to go to public school, much less a right to be transported there.

I mention my experience as a parent and that of my friend to illustrate the changes that have occurred in parents in the past 25 years. There have always been parent heroes, those who insisted on the very best for their children with disabilities, with or without the support of society. However, it is only since the enactment of federal and state special education laws that we parents have been able to view our children with disabilities as true equals, as equally deserving with other children, as children first and children with disabilities second.

Thus, the Education of All Handicapped Children Act (P.L. 94–142) brought a profound change in parents, a change that has been internalized and cannot be undone. This change may be as important as the legal tools to fight what we had known were injustices—exclusion and segregation of our children.

The role of parents in education goes to the root of modern special education—to Tom Gilhool. Knowing that children with mental retardation had a constitutional right to a public education and that the Supreme Court case, Brown v. Topeka, in 1954 declared segregation inherently unequal, Gilhool recognized dangers. He knew that placing mentally retarded children in regular public school classrooms risked having them relegated to the back of the classroom, ignored by the teacher and taunted by the other children—a danger that many parents fear again today as they think about inclusion.

Gilhool decided that the best way to protect the children was to give their parents unassailable rights in planning and monitoring their education: hence, the Individualized Education Program (IEP) and the procedural safeguards that were eventually incorporated in P.L. 94–142. These are the rights that parents must understand in order to assure that their children receive the best possible education.

Once the Education for All Handicapped Children Act (P.L. 94–142), became law, parents in various parts of the country recognized that they now needed new kinds of information and skills in order to make the law work for their children. No more bake sales to keep under-funded private programs in operation. Congress had declared that now the local community where the family lived and paid taxes must serve children with disabilities along with all the other children, and must provide an education that met the unique needs of each child.

These changes meant that parents had to learn all they could about educational assessment, educational planning, and teaching methodologies. They needed to understand a whole set of state and federal laws and regulations. They had to become acquainted with each new ideology and then assess its benefits for their child. They had to learn to communicate with school officials in new ways. No longer did they need to be grateful for every crumb; they could actually make demands on behalf of their children and expect reasonable responses to those demands. They could act as empowered partners with teachers and other educators.

The learning needs of parents transcended disabilities. The process for developing an IEP was the same whether the child had Down syndrome or dyslexia. While the Education of the Handicapped Act (EHA), renamed the Individuals with Disabilities Education Act in 1990, was going through the legislative process, the traditional disability organizations worked together as they had never done before, and parents began to see the commonalities of their children's needs across disabilities. As a natural outcome of this legislative activity and as a response to the new needs of all parents of children with disabilities, coalitions of parents began to form in various parts of the country.

Parent leaders at Closer Look, the project then serving as the National Information Center for Handicapped Children and Youth, recognized the need for change and encouraged the growth of these parent coalitions. In the mid 1970s, the U.S. Office of Education, then part of Health, Education, and Welfare (HEW), began to recognize parents' new needs. Officials at the Bureau of Education for the Handicapped (BEH) also realized that the new law could flounder and not meet its great promises for children with disabilities if parents were unable to perform their new role, or if the disability groups once again began to compete with each other for funds.

In Massachusetts, we looked at the Coalition for Special Education, the varied group of 42 organizations that had come together to lobby for enactment of our state's special education law three years before enactment of P.L. 94–142, and we decided to pull out those organizations that were statewide disability groups run by parents. From these we formed the Federation for Children with Special Needs, whose mission was, and is, to offer

parents of children with all disabilities the information and skill training they need to participate effectively in their children's education and care.

In 1975, BEH funded the Federation to operate a pilot Parent Information Center (PIC), and after the successful implementation of the pilot, the Office of Education funded four other PICs in Chicago, Cincinnati, South Bend, and Concord, New Hampshire.

Each of the PICs was operated by a coalition of organizations representing a variety of disabilities, with a board composed primarily of parents of children with special needs. We published newsletters, talked to parents on the phone, and sometimes accompanied parents to IEP meetings. Gradually we learned together that we would never have enough resources to help parents on an individual basis and we began to experiment with group endeavors, such as training workshops and annual conferences. The original parent centers proved to be so effective that BEH gradually funded more of them including Virginia, Minnesota, Georgia, Puerto Rico, Washington State, and California.

By 1983, the Senate Subcommittee on the Handicapped and other Congressional leaders also recognized the importance of informed, skilled parents in the education of children with disabilities. Leaders of the new parent movement helped draft legislation that would establish in federal law a national program of Parent Training and Information (PTI) centers. Since enactment, that federal program has steadily grown until there now are 60 PTI projects, with at least one in every state and in Puerto Rico.

As happens with so many efforts of this kind, the parent centers began with those who could afford to be involved and thus were disproportionately white, middle class, and female. However, almost from the beginning, the leaders worried that they needed to be more inclusive. They knew that many of the neediest parents were still left out. With an initiative from the House Subcommittee on Select Education, the PTI program is now expanding to include a component of experimental projects run by grassroots parents in dense urban areas and in remote rural sections of the country. At the same time, all the parent centers are working hard to serve the rich variety of parents in their states.

Leaders of the parent projects know that they are serving thousands of parents every year, helping them ensure the best possible education for their children. Yet, they get discouraged knowing that they can reach only a fraction of the parents in their states and knowing that large numbers of parents need one-to-one assistance that the PTI centers cannot afford to provide. They often feel that the law is not enforced as it should be, especially at the local, individual child level. However, they may not realize that their very existence and their day in, day out work help to ensure that this landmark education law actually works. Often their very existence encourages schools to do a better job.

While they continue to serve parents as they have always done, the parent centers are now moving to new frontiers. They are teaching parents new concepts like inclusion. They are also moving into subjects like transition, technology, team teaching, and cooperative learning. With the addition of Part H to the federal law, the parent centers will now move into the area of service for parents of infants and toddlers with disabilities. Those centers with experience in this area will be asked to help the others. The needs of parents of newborns and children with newly identified disabilities are different in many respects from the needs of parents of school age children. And, once again, parents must be informed and supported if this new law is to succeed, with its emphasis on family-centered services.

Another new area that the parent centers are embracing is self advocacy, the encouragement of young people with disabilities to speak on their own behalf. Operating on a peer basis, modeling has always been a key aspect of the parent centers. Thus it is not a difficult shift for them to view self advocates as important models for their young people with disabilities, including those with cognitive disabilities. PTI projects are now adding adults with disabilities to their boards, and several are adding them to their staffs as well. The parent centers recognize the importance to parents and to students of exposure to successful adults with disabilities.

Twenty-five years ago, when children could legally be excluded from school, parents and children almost never saw successful adults with disabilities. Those who did miraculously manage to get an education suffered incredible discrimination. Neal Pike, founder of the Pike Institute at the Boston University Law School, speaks of his experience as a blind lawyer. He had great difficulty renting office space because landlords refused to rent to a blind person—legally! He was not allowed to enter the local movie theater because of his blindness. We parents today need to be reminded of such stories, and we also need to hear from today's students and graduates.

Supporting Families: *What They Want Versus What They Get*

Susan O'Connor

Center on Human Policy
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Introduction

Providing support to families who have children with disabilities has taken on many changes in the past 15 years. In 1988, 42 states provided family support services (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). The percentage of these funds, however, amounted to only 3 percent of the total budgets of Mental Retardation/Developmental Disability agencies (Fujiura, Garza, & Braddock, 1990). Some states have passed or are working on legislation to develop more supports for families. Described as family-centered and family-determined, these supports place the family at the center of determining their needs. The meaning of support to families and especially families outside of what is considered to be mainstream middle class culture needs to be further examined.

This article attempts to understand the meaning of family supports to four families of different racial, cultural, and socio-economic backgrounds. Two of these families are headed by single mothers and the other two by both parents. Though each is very different in make-up and life experiences, this article compares what each family defined as its needs with the kinds of services that were offered. It first looks at the common experiences of families who have a member with a disability and then some issues that arise for families who are considered to be outside of the mainstream in this country.

The article is based on qualitative research methods (Taylor & Bogdan, 1984). The author collected data with family members over a three-year period using formal and informal in-depth interviews and participant observation. Observations took place in families' homes, on outings, in group homes, schools, and in agencies in which the families were involved.

Families' Experiences

The discrepancy between what families want and what they get in their attempts to acquire services is often great. For the four families in this study, their main concern ranged from respite, to financial assistance, to transitional services from the school into the work world. What they received from family support services seldom matched their needs and wants but rather reflected their perceived needs as determined by those agencies and workers who entered their lives.

Needs of the Family

A common theme in the lives of these four families was how they viewed their needs in terms of their family as a whole. Each family focused on their entire family as opposed to the child with the disability. For example, when discussing their life today, one family did not discuss how it had changed when they had their son who is labelled with autism but rather how their lives changed because of having children. The father said:

> *"We used to do a lot of things, we would go out from time to time . . . we haven't done that in years. Now all of our time is spent for the children."*

The day to day struggles that went on in their lives were also important. Struggles such as making ends meet, health concerns of different family members, single working mothers dealing with kids who are sick and need to stay home from school. Worries about the future and how their children will fare.

What Families Get

Day to day problems that emerge in the lives of all families are often things that remain private, known only within the family or among close friends and relatives. When, however, families request services, their personal problems become public issues to be dealt with by formal agencies. Receiving assistance often involves a process of changing the family identity where they are seen as clients (Gleidman & Roth, 1980, Sonnenschein, 1984), judged as good or bad parents, and offered teaching and advice.

In the role of client it becomes clear that there are certain rules they must

The Barlow Family

Jimmy and Jake Barlow are the two youngest in a family of six. They live with their mother, Pam, and two sisters in a middle class suburb of a city of about 150,000 people. The oldest daughter Jane recently moved in with her father who has not lived with the family in four years. The Barlows are of European American descent. At the time of this study, Pam owned and operated her own small business. Both Jimmy and Jake have are labeled severely multiply handicapped, a diagnosis given to them shortly after birth. Pam's desire to keep them at home caused her and the children's father to separate and divorce. Pam explains: He wasn't involved from the day the boys got sick. He called them things and couldn't accept them... I kicked him out. I made a choice to keep them (the boys)!" For the past six years, Pam has cared for her family alone. Over the past year, life in the family has changed as Pam has decided to marry a man who has grown close to her sons. She, however, questions what she should do. "I have thought of finding a place for Jimmy and Jake, but he insists they stay with us." Beth's main concern was with getting respite support for her family.

The Henry Family

Verna and Nate Henry are heads of a family that can best be described in one word: proud. They moved to the north from Florida twenty-five years ago and have raised three sons, ranging in age from nine to twenty years old. The Henrys are African American. They

abide by and demeanors that they must acquire. The acquisition of such roles develops subtly over time through worker and family interactions. People who become clients are thrust into a dependent and passive role in relationship to their caregivers or the people that support them. According to Bush (1988), the role of client, frames a person in a way that the most significant aspect becomes one of need. He says that services sometimes concentrate on means at the cost of ends with an emphasis placed on a deficit and the need for something to be corrected. In this case it is the family that comes under scrutiny. Families are often aware that they must give something up. For example, one mother said, "You know I'm a private person and don't appreciate having to divulge all of the personal information." Families' attempts to receive services often puts them in the same status as their son or daughter. They now need therapy and to be fixed (Gleidman & Roth, 1980; Turnbull & Turnbull, 1986). At a meeting one worker told a family:

"I will be working with you for only a few more months. I would like to work on organizing... all of your relationships, between you and the kids, you and your wife and the kids.... After this I will step back and see if it. is necessary that I am here..."

From Good to Bad Parent: The Continuum

The concept of the continuum is pervasive in services for people with disabilities. (Taylor, Racino, Knoll, & Lutfiyya, 1987). Like people with disabilities, families are often placed on a continuum according to their presumed parenting skills and competence to manage their lives. A families' place on this continuum changes based on the judgements of the people working with them and their perceptions of how the family follows the rules of the system. These judgements and perceptions are based on the values and standards of people outside of the family, on professionals who bring their own unique experiences and problems to their work (Deluca, & Salerno, 1984). In one family the father changed from being defined as the good parent and his wife as "needing a lot of work," to each taking the opposite roles because concerns expressed by professionals about the father and how he adhered to their suggestions. In another family the mother

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was reported for abuse by a teacher because her child came to school with a bruise. Even though the mother was a well known advocate in her community, she was not asked what happened to her child but was immediately reported, she explained:

"One of the boys got spanked for tipping over the T.V. You know, he could have been killed doing it and they mark very easily, if you put em' in lukewarm water they come out all red. So I spanked him to scare him and he went to school and the teacher saw the red and called the police. She turned me in for child abuse, we were interrogated the whole nine yards."

While the issue of child abuse should not be taken lightly, this situation could have been resolved through a simple call. However, the teacher had previously judged this mother to be a bad uncooperative parent.

Learning the Rules

Families quickly learn how and when to demonstrate behaviors acceptable to human service workers to be viewed as following the rules or as "good parents." This is true when workers enter their home and when their children go outside the home.

Families also recognize the need to have the house in order. In one situation a worker commented about the mother: "She always has the house clean." When I visited the house at times workers were not expected, the house was in more disarray. The mother learned quickly what she needed to do when she was visited.

The Impact of Culture

Having a family member with a disability renders families vulnerable to the system. Families who are from ethnic and/or socio-economic groups outside of the mainstream, or are headed by a single parent or a parent with a disability often face another level of scrutiny (Harry, 1992). They not only have to become good parents by middle class standards, but their ethnic and socio-economic identities are called into question.

The Meaning of Labels

It is difficult to break away from the boxes, and criteria that place people into

have gone through a number of ups and downs financially and presently are "struggling to get by." Both parents work full time and even with that can "barely make ends meet." In the quiet of their home, talk concerns current health problems of Verna and the need to be out of work after surgery. Verna expresses anxiety about how all of the bills will be paid: "We just keep gettin' in the hole it seems, (but) we keep gettin' by."

It is difficult in talking with Verna and Nate to know that their youngest son has been labeled autistic. Though outsiders might observe a "difference" in Chas—things such as rocking or screeching noises—his parents never talk about that label or how Chas is different from his brothers. Instead they focus on similarities. Nate explains: "Chas takes right after me. He gets up a lot. He can't sleep either so we're up together. He got that from me." Nate explained with pride that his two younger sons are known all over: "When I go to the store, I never get out without someone comin' up... saying, ain't you Charles' daddy, or ain't you Mitchell's daddy? Everybody knows em." A major concern to them was to receive financial assistance.

The Salah Family

Twenty-three-year-old Thomas is the only son of this Lebanese American family. He has three sisters, one older than he and the other two several years younger. The three daughters live with their mother, Clare, and grandmother in a middle class neighborhood. The Salahs came to this country twenty-five years ago. Mr. Salah has since died. Clare continues a part-time job as a seamstress. Thomas was born with Down's syndrome and, until a year ago, lived at home with his family.

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which is common in Arab culture. His mother describes what life was like for him when he lived at home: "He knew everyone in the neighborhood, people we didn't even know . . . the group home, there is a difference between that and home." Clare Salah had sought out transitional vocational services for her son.

The Valdez Family

The Valdez family moved to an upstate community from New York City, where their children were born. Sylvia and Jose are natives of Puerto Rico. The Valdezes live in an area of the city known to be home to the Latino community. Sylvia, who has been given the label of either mild or moderate mental retardation—a label she shares with one of her children—is in charge of taking care of the home and children, although Jose is the key communicator and facilitator with the system. Jose does not work in the traditional sense; he does some property management for a relative. Several family members also receive Supplemental Security Income (SSI). The Valdezes sought respite care for their children.

The Families

	What They Want	What They Get
Barlow	Respite	Placement in ICF/MR facility
Henry	Financial assistance	Minimum financial help
Salah	Transitional vocational	Job placement as well as group home placement
Valdez	Respite	Some respite, possible out-of-home placement

categories. Once a label has been assigned, there are limitations on how that person will be perceived and treated.

In some families disability does not present a major problem but rather becomes part of who they are as a family. This is true in many cultures. In these families the child is not viewed totally as disabled. Disability becomes a public issue only within the structures of the system that defines it. In the Henry family, Chas was seen as a member of the family. His actions, typically described by people in the system as "autistic behaviors," were described by his family as moods, phases, and habits that he was going through. When discussing how much their son liked things to be the same, otherwise known as ritualistic behaviors typical of autism, his mother said: "He likes things to be the same you know, kind of a habit."

Harry (1991), discusses the difficulty that Hispanic families have in accepting label designations especially labels that indicate mild learning difficulties. They may be interpreted by the family as inappropriate especially if they see the child socially meets cultural norms. For the Valdez family after a meeting with a committee on the handicapped where the issue of the label of their child came up in relation to next years placement, his question after the meeting was: "What is this mild and moderate mental retardation anyway?" To him, his children played with their peers in the neighborhood and though he might acknowledge his children had needs in many ways, he had similar concerns as any parent would of the future of his child. Though an outsider might understand why these children were labeled, to these parents it was not always so clear. In contrast, Pam Barlow had worked hard to learn the language of the professionals and talked about "integration . . . functioning level . . . and high seizure activity." This was language that she learned early on in order to work within the system. While it is important for parents to understand the system in which they must work, it is equally important for professionals to understand the effect that labeling has on children and families. While public explanations and treatment for disability are based on medical and professional views and are often linked to cause, private explanations allow for many causes (Joe & Miller, 1987) and have a broader capability for acceptance. Labeling often creates or reinforces a negative image.

The Loss of Cultural Identity

Many people with disabilities receiving services are viewed in terms

of their disability labels. This often determines the treatment or intervention. Workers and professionals do not look beyond the label to see the ethnic or racial identities of people with disabilities and their families. Thomas, a young Arab American, was very fond of Arab music. While talking to a staff member at the group home in which he lived, I asked if he listened to Arab music there. With a puzzled look on her face, the staff person said, "Oh, is he Arab?" Language too is an important aspect of one's identity. In the Mendez family, the mother spoke no English yet was the primary caretaker of her children. In school, the children were learning English and almost always refused to speak Spanish with their mother who said, "They don't listen to me." Though there may be a number of factors that account for this, the children were learning to devalue the language of their origin and a strong part of their identity.

Conclusion

Every family has their own life circumstances that shape who they are as individuals and as families. Ethnic, racial, socioeconomic, and ability differences vary as greatly among families as they do among the people who come into their homes to offer them assistance. Individual identities of every family vary significantly yet what the families in this study were given did little to reflect that individuality. From the more simple requests of respite, financial assistance, and transitional services came advice and teaching, judgments about being good or bad parents, and rules set by people outside of the family. In addition, in two of the families, placement outside of the home occurred though it was not the initial objective of the family. Through all of the battles over obtaining respite and support, Pam Barlow after being strongly supported by professionals in her decision to finally place her children said, "It has been a long struggle though and I'm tired of fighting."

For the Salah family, placement occurred under the guise of what often naturally occurs in this culture— moving out on your own. Yet in Arab culture it is more natural to remain with family. The decision was difficult for Clare Salah who said: "They encouraged me to put him there now because . . . it was a nice group home and this kind of opportunity might not arise in the future." Thomas was removed from the neighborhood he grew up in and the connections that he had made. Though the Valdez family received some respite along with a large number of people trying to provide support, the situation of the children remaining at home remains tentative. For the Henry family, life goes on yet their financial difficulties have not lessened.

The discrepancy between what families think they will get when entering the service system becomes greatly skewed as their time within that system grows. For many families, we must examine the additional vulnerability that results from their race, ethnicity, or socioeconomic status. Professionals must begin to develop a posture of learning about the differences in families rather than attempting to mold all families into one definition of what is a "good family." Without this posture, it will remain difficult to provide truly family-centered and family-determined supports. ♦

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A Family-Responsive Approach *to the Development of the Individualized Family Service Plan*

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Part H of the Individuals With Disabilities Education Act provides for early intervention services to children with disabilities who are under three years of age. Part H, while in many ways consistent with Part B which mandates services to children with disabilities between the ages of three and twenty-one, has several unique provisions. These include requirements for services to be family-centered rather than focused solely on the child; for case management or service coordination to be provided to assist the families in identifying and utilizing appropriate services for themselves and their chil-

"From my perspective as a mother, the Individualized Family Service Plan (IFSP) as the Beach Center has developed it, is very sensitive to the well being of the family as a whole and to the individual family members. No one is overlooked. Natalie's needs were balanced with the family's needs, recognizing that the family must be strong to meet her needs adequately. We talked a lot about me and whether I felt I could handle the work demanded by the various potential programs in her service plan."

"This approach to the development of a service plan has been radically different from others we've participated in. In those, the more needs of the child that were identified, the more work and responsibility were added to us. It felt like a heavy weight. Even services which were supposed to help Natalie created demands for transportation, for time, for arranging and rearranging schedules, as well as for financial obligations. Even "free" services meant money was needed for childcare for our other child or for gas to get there and back several times a week. Other approaches did not address these needs that our family had, but this IFSP did. During the development of the IFSP, we looked at ways to provide the services for Natalie without interrupting everything that was happening at home. This way our needs were met, as well as Natalie's."

"The approach also helped us think about our relationship with Natalie and to view her as a part of the larger community. We have moved from looking at her as a young child in our home to someone who has a place in the community. She can go to school; she can be around children her age. Now that we realize that Natalie can give as well as receive in these relationships, we do not feel hopelessly indebted to others who help in Natalie's care. We recognize that people enjoy being around Natalie and working with her, and with us. That they benefit from this "togetherness," just as much as we do. This new attitude toward our circle of friends has relieved our fear and we are more willing to ask others to help. Now our approach is to encourage others to see our vision and to become part of the team effort."

(Comments on the IFSP development process by Leslie Jones, the mother of two youngsters, one of whom has a severe disability.)

Photo by Beach Center

dren; for interagency coordination to facilitate a broad range of services with the least amount of duplication and bureaucratic interference; and for an Individualized Family Service Plan (IFSP) to be developed which provides a plan for the early intervention services as well as other services that will improve a child's developmental status.

The Beach Center on Families and Disability, at the University of Kansas, under the direction of Ann and Rud Turnbull, has been developing a model process for a family-friendly Individualized Family Service Plan (IFSP). To be family-friendly, there must be procedures which are responsive to the priorities and concerns of the whole family. The Beach Center model for the IFSP has evolved from input from family members and service providers alike, as well as the use of the model with families by Beach Center staff members.

In developing this IFSP, staff members wanted to create an IFSP form and process that reflected the wishes of families as well as those of service providers. Staff members from the Beach Center conducted a number of focus groups with families of children who were in early intervention programs to find out what they wanted from the programs. The results of these focus groups indicated that families wanted several things from early intervention beyond those services directed at child development (Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, & Siegal-Causey, 1990). Comments from the focus group indicated that families look to the early intervention specialist for emotional support and friendship; looking more for interdependence than independence. This combination of emotional support and professional support may be a new and challenging role for professionals. Training programs and service programs often caution professionals against becoming "friends" with the families, and advise them to maintain a professional distance from those with whom they are working (Turnbull & Turnbull, 1990). In addition, in providing this support and friendship, families wanted professionals to be sensitive, nonjudgmental, and accepting of families' diversity; to allow them to be the ultimate decision makers but to recognize that their readiness for decision making may vary from family to family and issue to issue; and to promote interagency collaboration so that families can obtain services efficiently. The preference for emotional support and friendship is clear in the families' comments regarding the assessment of strengths and needs. They preferred a process that might be more aptly described as "sharing family strengths and needs," rather than "family assessment."

> *At first, I was tense with the professional coming to my home. But it was a nice little conversation. The professional's mannerisms and the way she asked questions was like we were sitting down for a cup of coffee. She got a lot of information without asking* (Summers, et al., 1990, 87).

The families felt that the sharing of strengths and needs was really a part of the intervention and should be tied to meeting the child's needs. Also, in terms of whole family and individual

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well-being, families mentioned the need for friendship most frequently, wanting the early intervention programs to help them develop a sense of community or belonging with other families who have children with similar needs and with their community as a whole. Parents of younger children also emphasized their need for information while building family-professional relationship skills. Meeting needs for general family well-being were mentioned by families of older children.

The IFSP model of the Beach Center is based on these preferences and has as its backbone a "Listening and Sharing" process. Individuals, when they speak of professionals who were most helpful to them or with whom they felt a "partnership," speak first of that professional's willingness to listen to their concerns, to empathize with them, to take time with them, and to share common experiences with them. Throughout this model IFSP process, the service coordinator is listening for family preferences, facilitating the expression of those preferences, and then assisting the family to act in concert with their preferences to best meet the needs of their youngster and their family.

In the first meeting, listening and sharing begins with the service coordinator obtaining information from the child's "story" which includes the things the family enjoys about the child, his or her strengths, and the family background including important people and events, concerns they have, and other characteristics of the family relationships. At this meeting, the service coordinator and the family also begin to talk about the family's To-Do list, or the outcomes which the family wishes to achieve. This meeting is one of the initial steps of the family professional partnership. Parents report that no one has ever asked them to think about what they enjoy about their children. Helping families build great expectations for the future and affirming the positive contributions of the children to their families and communities are important goals at this stage of the process.

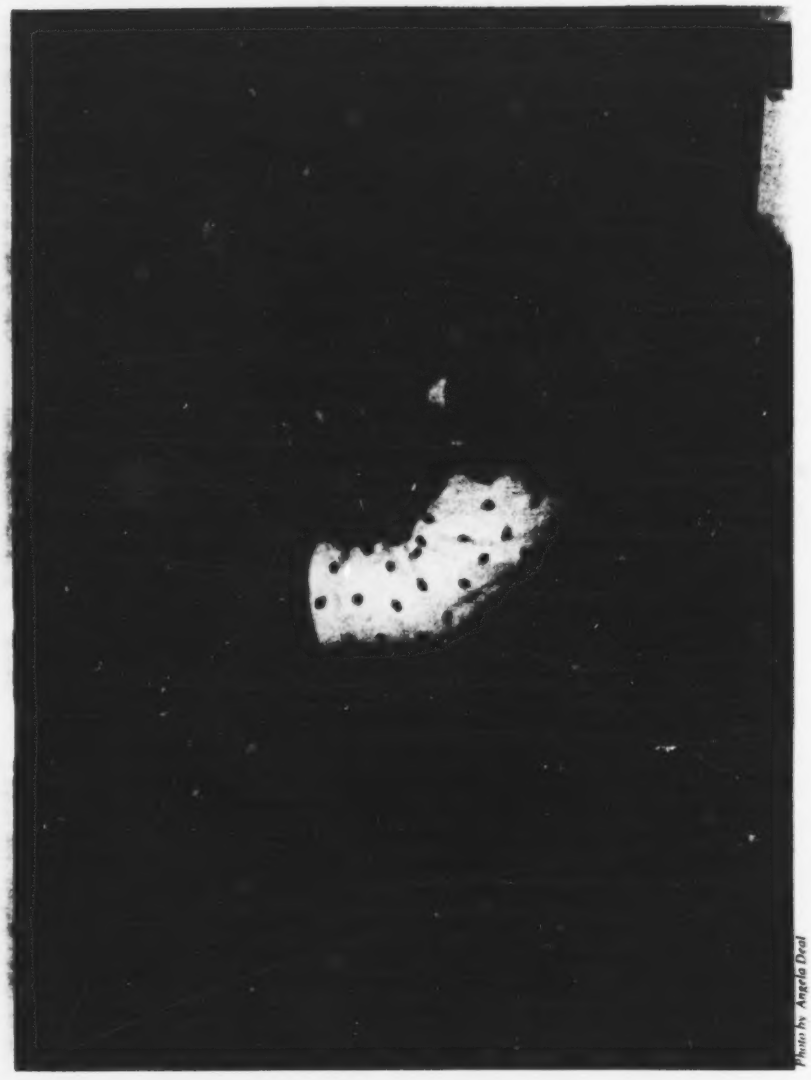

Photo by Angela Deal

As a part of this meeting, or in one scheduled shortly after the first, an interim IFSP may be developed so that early intervention services can be started immediately for the child. The interim IFSP can be drawn up to start services while the evaluation process is being completed.

During these first discussions and meetings, the service coordinator and the family also plan a complete evaluation of the child. Remembering that one of the requirements of the IFSP is that it is family centered, the service coordinator asks the family what they would like to learn from the evaluation and what level of involvement they want in the evaluation.

After the evaluation, a time is set to discuss the results with the family in a setting that is comfortable to them. Their questions are answered honestly, without jargon and with an emphasis

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on the child's strengths. The specific tests that were used also need to be explained. This information can then be entered on the IFSP form if the family wishes.

The IFSP can be drawn up in a meeting with as few people as the parents and the service coordinator or as many as the parents wish to have attend including extended family, friends, other professionals, or clergy. We like to think of this meeting as a coalescing of a Circle of Friends (Perske, 1990). Thus, rather than being professionally dominated, there is roughly equal representation by professionals, family members, and friends. During the IFSP meeting, everyone present contributes ideas for a plan of services to accomplish the family's To-Do list or the outcomes they want for their child. These outcomes are discussed during the IFSP meeting and the final outcomes for the child and family are identified. To achieve these outcomes, a plan of services is developed including any of the fourteen early intervention services (Table 1) and other services that may be helpful to the family.

> *During the IFSP, I talked about how difficult it was to get Natalie up and ready for school every day and to transport her since the school bus would be hard on her physically. The friends and professionals at the meeting discussed schedules and days and came up with a plan for them to help get her ready and to school. I never had to actually ask any of them to volunteer. They just "worked it out" to help me as well as Natalie.* (Leslie Jones)

The complete plan for implementing early intervention services must be included in the IFSP. As a part of the IFSP development, the family can also talk about the resources they have to accomplish the outcomes and any needs they may have in achieving them.

Table 1. Early Intervention Services

- Audiology
- Family services coordination
- Family training and counseling
- Health services
- Medical services for evaluation
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Social work services
- Special instruction
- Speech language pathology
- Transportation

In addition to developing a service plan for a child and his/her family, the Beach Center model affords families an opportunity to develop skills that they can use during the entire life of their child. Specifically, throughout the development of the IFSP, strategies are used to assist the families in the development of wise choice making and of social networks and friendships.

The process initially promotes the family's development of friendships through a modified use of an eco-map. During the IFSP process, as developed at the Beach Center, the eco-map is first used to provide a structure for the family's identification of current network members who might be of help in suggesting resources or in helping to access these resources. Secondly, the eco-map is useful in identifying potential friends who could enrich the network. This use of the eco-map helps the family and service coordinator identify resources that for one reason or another have not been previously accessed but potentially could provide information and assistance to the family.

The model utilizes two approaches to the development of wise choice making. First throughout the IFSP process from the beginning to the end, the family service coordinator models a systematic decision-making process. In this modeling, she/he frequently asks, "What are your options" and "What are the pros and cons?" Secondly, during the IFSP meeting, a systematic approach to decision making is used for items on the To-Do list that present options and all of the team members are encouraged to suggest ways of getting the To-Do list, Ta-Done. The steps in this process of creating choices include setting the child's or family's goal; determining how you will know the goal has been accomplished; looking at options; identifying the resources for these options; choosing a plan; and evaluating the plan.

The IFSP is a form and it is a process. Care must be taken that, with the demands of time and bureaucracy, the IFSP does not become just another form to be completed. As implemented in the Beach Center model, the IFSP process provides not only a service plan for the child and his or her family, but a process that helps the family build strategies that they can use to assist them in managing other challenges and opportunities.

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Project Vision: *Outreach to Infants in Rural Settings*

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Photo provided by Janet Brown McLaughlin

Introduction

Periods of change create an exciting and adventurous time. The events of the last few years in early childhood special education have been particularly dynamic. With the passage of Public Law 99–457, the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act Amendments, early childhood professionals and parents have had the opportunity to make best practice a reality. Our best concepts and highest dreams for quality programs for young children with disabilities are represented in this landmark legislation. The difficult task before us now, is to implement the intent rather than become consumed with the letter of the law.

A national outreach project entitled Outreach to Infants in Rural Settings (now Project Vision) is designed to address the particular needs of rural educators and families as they accept the challenge presented in the imple-

mentation of this new legislation. Since the initial funding by OSERS in 1988, Project Vision staff has presented numerous workshops and provided extensive in-depth consultation to rural service providers working with the birth to eight-year-old population of children with disabilities and their families. We have offered training on the components of Family Guided Service, the Team Building Process, Service Coordination, Screening and Monitoring At-Risk Infants, and Transition and Multicultural Issues.

Target Population

Our primary target area has been the rural states of the north and central portions of the United States. We have offered extensive consultation and follow-up to locations in the states of Idaho, Washington, South Dakota, Minnesota, and Montana. Our services range from technical assistance to local interagency councils, and consultations with state education department personnel, to hands on assistance in the classroom or meeting room. We frequently present to parent organizations and school or agency conferences. The large group workshops have been instrumental in enhancing public and professional awareness, but they often do not promote the long-range interactions necessary to support systems change. To achieve this goal, project personnel have sought to develop long-term relationships with local districts or agencies that are committed to the change process. To date, we have formed long-term relationships with twenty-four locations. This close working relationship, extended over a two- or three-year period of time, has fostered an individualized approach to the delivery of technical assistance and often results in observable changes in the delivery of service.

Technical Assistance

We believe in the concepts and ideals contained in Public Law 99–457 (IDEA-Part H). So much so, that we have designed our service delivery system to mirror the concept of "individualization" proposed in this legislation. Just as the family of each child with a disability has its own unique strengths and possible needs, so do the people, programs, communities, and states to whom we offer information, assistance, and support. Our goal is to facilitate the identification of current strengths and compare or contrast them with the perceived ideal or vision of the local service agency or district. Our assessment process helps agencies crystalize their goals and evaluate their direction towards growth. The ensuing technical assistance activities are then designed to strengthen and build upon resources to enhance a change in the system that reflects current best practice and recent legislation. This process of individualizing service is enhanced by the use of an assessment tool designed to gather information and direct the goal setting process.

Photo provided by Janet Brown McCracken

Determining Technical Needs

When designing individualized training on a site by site basis, it is essential to be able to efficiently gather information on the existing strengths and needs of the prospective training location and personnel. To guide the systematic collection of this information, project staff developed the Best Practice Inventory. This interviewing tool is a sequential listing of observable items which reflect best practice in the areas of child and family service planning and delivery (see Figure One). Project Vision staff rate each site on an item by item basis through observations of the services, interviews with the staff, and where possible, interviews with parents whose children

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were enrolled in the program and through the review of program documents such as children's files, parent handouts, and program manuals. Staff from the prospective training site participate in this information collection to ensure the necessary sense of partnership between technical assistance trainer and prospective trainees and to decrease the number of inaccurate ratings due to misconceptions, or lack of pertinent program policy or action. At the conclusion of the observation and interviewing process, training staff discuss the outcome with key program staff, and together decide on a course of action for growth that will incorporate best practices where needed. Project personnel seek to build on the resources of strengths of the program while acknowledging the mutually identified areas of need for growth. Due to the recent passage of P.L. 99–457, many sites have not yet incorporated all components of the law. Programs, for example, had no evidence of an Individualized Family Service Plan or had assigned service coordinators with the specific roles delineated in the legislation. However, the obvious lack or existence of a family centered approach or active case management system could be used to determine what level of technical assistance might be needed to assist the personnel requesting training.

At the conclusion of the evaluation process and review of the material gathered, project staff and site personnel reach agreement on the following issues. First, what are the agreed upon needs of the site? Second, what resources are available, on site, to meet the needs? Third, is training or technical assistance required to meet those needs? Project Vision staff encourage prospective trainees to look at local resources and existing expertise for ongoing support. Project Vision personnel can then act as consultants in the application of information or providers of information. Some sites elect to have our project deliver training and follow-up consultation without any local assistance; others request only follow-up consultation; still others want more training and minimal follow-up. These mutual decisions, and a plan for the type and sequence of the delivery of training is recorded on an action planning form (see Figure 2).

At the conclusion of our first year, eight rural sites had contracted with us for services on a long-term basis. We maintained an eighteen to twenty-four month partnership with these original eight, while gathering seventeen more in-depth contacts with additional sites over the next four years. Our assessment process made it possible to individualize the planning and delivery of technical assistance plans, note changes in the system, and evaluate growth over a period of years. At the conclusion of the first three-year cycle of OSERS funding, the Best Practice Inventory tool was used to collect post evaluation data at each of the sites. Statistical analysis of these pre- and post-data indicated a significant change in scores in the areas of family involvement, goal setting with families, assessment of family outcomes, and Individualized Family Service Plan (IFSP) process. The collective growth of all the programs is impressive and each program's story is unique. Following, is a case study of one program's growth.

Case Study

The Progress Center, located in Longview, Washington, has served the birth to three population of children with disabilities and their families in that community for more than thirty years. Progress Center is a private, non-profit corporation with 15 employees. During the initial assessment process, it was apparent that this program was family centered, current in their practices with young children, and well respected in the community as a resource for other agencies and schools. Children's programs reflected best practice in assessment procedures and curriculum but lacked a transdisciplinary focus due to the splintering of service delivery. This was due, in part, to the part-time status of ancillary personnel and the lack of time allocated to staff meetings. Administration and staff seemed open to the changes needed to achieve compliance with Public Law 99–457, but were uncertain of the direction in which they should move since state policy had not solidified and the local Interagency Coordinating Council had just formed. Through the evaluation and discussion process the following goals were identified:

1. to receive training on the IFSP process and obtain assistance in developing a new form for the Center;

2. to analyze staff patterns of interaction and communication around the planning phase of service delivery and to determine an efficient means for the on-going exchange of information regarding children and families.

In response to these requests, Project Vision staff prepared and presented three consecutive trainings on the IFSP process. The outcome was a new form designed to meet the multiple needs of the variety of funding resources supporting the Center and a procedure for intake of families which allowed for time to gather information on family strengths and needs (concerns, priorities and resources). The previous existence of a family centered approach at this program facilitated the rapid movement by the staff and administration.

During the IFSP training, it became apparent that the first goal of IFSP development and the second goal of increased communication among staff members could not be separated. The lack of time for communication and staff meetings was inhibiting the development of the IFSP process. Since staff did not currently have designated times to meet and plan, the notion of team assessment, and a transdisciplinary approach to services for the whole child seemed only remotely possible. Since staff did not communicate as regularly as they liked, service coordi-

Photo by Janet Brown McClanahan

nation was sometimes disjointed and service delivery fragmented. A major issue contributing to the circumstances was the scarcity of resources. If staff time were to be allocated to planning, valuable service hours and associated revenue from insurance and Medicaid would have to be decreased. The other resource that was seriously lacking was time. Support and ancillary personnel were one quarter or half-time employees, some with other job responsibilities during the day or week. Some staff had not budgeted the necessary time to the Progress Center to allow for crucial planning and meetings associated with successful collaboration. If we were to meet the first and second goals, major policy changes and reallocation of resources would have to occur.

Progress Center staff reached agreement that they would need to streamline their system of day-to-day communication and commit major resources of time and money to allow for periods of cooperative planning. Paid staff meeting time was scheduled for the upcoming fall when part-time personnel could renegotiate their commitments to other jobs. Day-to-day communication regarding changes in children's progress or family goals were delineated by bright pink paper and placed in staff mail boxes of those who "needed to know." The color coding helped facilitate the fast routing of information and enhanced the collective spirit of the service team. Meeting time was used on families, to discuss major changes, team access, or meet with a parent. A group of disengaged resources personnel were joined together into a more cohesive, time efficient team of cooperative decision makers.

Now that the team had become a more collective working unit, they began to examine themselves and their roles on the service team. This lead to a new goal, the request for assistance in team development. A staff retreat was scheduled and a team development training was designed to encourage personnel to identify individual talents and to acknowledge areas of professional growth. The concept of long-range planning and a series of two-year goals for the Center was introduced. Since the retreat was attended by advisory board members as well as staff, the goal setting and subsequent planning was highly productive. At this point we were able to reassess the need for technical assistance from Project Vision. It was decided that a consultant from the local mental health agency would serve as facilitator to the staff on team interactions on a monthly basis and that assistance from Project Vision staff be confined to new topics. This arrangement allowed for a more consistent use of consultation time and was cost effective.

In a post evaluation interview conducted at the conclusion of the first three-year OSERS funding cycle, Progress Center was reevaluated using the Best Practice Inventory. Through the observation and interview process, post data were collected to determine the amount of change made at the Center and if the identified goals had been achieved. Progress Center had made substantial changes in policy and procedure. The interview also served to identify future goals in the area of collaboration and curriculum which are being worked on today. This small rural Center continues to be "progressive" in its implementation of high quality services for young children with disabilities and their families.

Summary

The Progress Center staff are representative of the many rural programs engaged in long-range planning and improvement with the cooperative assistance of Project Vision. These programs represent the best of early intervention, and demonstrate quality through commitment to change. Project Vision staff continues to offer their support, information, and ongoing consultation in this thoroughly exciting process.

Angles of Influence:
Relationships Among Families, Professionals, and Adults with Severe Disabilities

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One of the most significant cultural features involved in a person's transition from childhood to adulthood is a gradual change in the relationship between that person and his or her parents (or caregivers). While noting the broad range of perfectly appropriate relationship patterns between parent and child that can characterize this transition process, it is nonetheless clear that a culturally valued outcome of achieving adulthood is some version of increased independence and self-determination. Equally valued from most parents' perspectives is the realization of a reduced level of daily responsibility as a child gradually becomes more autonomous. When the individual has a severe cognitive disability, however, following this pattern of personal autonomy and family separation can become very complicated. Issues of independence and self-determination must be balanced by considerations of experience, information, and personal judgment. Parents often must balance an acknowledged need to "let go" of their newly adult son or daughter with an equally strong sense of urgency that their continued advocacy and involvement is essential to obtain adequate supports from the adult service system.

When involved in this process, the adult service professional often faces difficult decisions in defining what an appropriate relationship with the family of an individual with disabilities might look like. While family-professional relationships in general have received a lot of attention from researchers, practitioners, and family advocacy groups, most of this has focused on the relationships when the person with the disability is still a child. Yet, for a variety of reasons, especially inadequate or nonexistent alternatives, families often remain the primary support network for adults with severe cognitive disabilities. Even if adults with such disabilities are living outside their family's home, and even if they have a job of some sort, their families often remain actively involved as the legal guardians and/or primary advocates for creating and preserving the formal and informal supports needed to maintain that quality of life. Families of adults with disabilities and the professionals involved in providing formal support to them will always have substantial and ongoing relationships with each other. As a field, however, we do not have an adequate understanding of how members of these two groups (i.e., family members and professionals) view their current interactions with each other. That basic understanding seems essential before we can begin to define and support more appropriate involvement of professionals in the lives of these families as part of the formal support system.

The *Supported Families Research Project* (SFRP) at the University of Oregon is trying to expand that basic understanding. Funded by the Office of Special Education and Rehabilitative Services, SFRP is currently in its third and final year and has two basic objectives: first, to develop a grounded theoretical interpretation of how professionals and families of adults with severe disabilities perceive their relationships with each other; second, to build on that interpretation to design and field test a package of guidelines and strategies that adult service professionals might use to improve their interactions with the families of the individuals they serve.

This report focuses on the first of these objectives by describing the variety of perspectives we have encountered on current relationships between individual families and professionals. Even within this focus, however, the findings reported here will deal only with the final element of the three-part theoretical account of family-profes-

sional interactions that has emerged from our research: the relational outcomes in terms of patterns of influence. We will briefly characterize our findings about the two other elements of interpretive approaches and interactive events that we believe contribute to the perceived relational outcomes.

Qualitative Case Studies

The research focus of this project builds on previous research by the project co-directors (Ferguson & Ferguson, 1986; Ferguson & Ferguson, in press; Ferguson, Ferguson & Jones, 1988). That earlier research looked at families' perspectives on informal support networks, while the current project turns to the complementary role of formal networks. What is important here is that we believe the earlier research demonstrated the power and utility of qualitative research methods when trying to understand the multiplicity of variables that go into the social construction of family relationships. Indeed, recent qualitative research has made several significant contributions to this type of naturalistic insight into the "social construction" of family life (Charmaz, 1980; Fine & Kleinman, 1979; Geertz, 1983; Stack, 1974). The qualitative capacity to incorporate both the complexity of circumstance and the nuance of personality into an interpretive and holistic description remains essential to this project as well. One of the strengths of qualitative methods for such a situation is that it allows the researcher to avoid the premature elimination or neglect of certain variables in favor of others through extended, unstructured interactions with a small number of research subjects. As one respected ethnographer of school life has described the guiding belief of such immersion into a natural setting:

"One individual's responses and experiences, even one utterance, may reveal more about a 'cultural form' than a whole scientific survey of 'attitude.' And the truth or not of this must partly be in how it touches others' experience in its reception." (Willis, 1981, p. 218)

This strand of the SFRP research effort has used standard ethnographic or qualitative techniques to gather naturalistic information about how family members and professionals in the formal support system perceive the nature and quality of their interactions with each other. For the past two years we have made frequent and regular visits to two counties in Oregon. In essence, each of the counties has become the site of a self-contained case study of how professionals and families within a clearly defined setting interact with each other and how they interpret those interactions for others. In each of the counties, we have used participant observation and intensive interviews as the primary techniques of data collection (Bogdan & Biklen, 1992; Taylor & Bogdan, 1984; Lofland & Lofland, 1984). Across the two counties we have conducted over 80 hours of intensive interviews adult service professionals, family members, and adults with disabilities. In addition, we have conducted over 23 hours of participant observations in such contexts as formal planning meetings, parent advisory group meetings, and staff meetings of various types.

The Settings

Ocean County combines several interesting features for one case study. First, it is a large, rural county. The total population is under 40,000. The economy depends on the fishing and tourist industries. The official number of persons with developmental disabilities is small compared to some other locales. However, this also means that the number of professionals involved in disability services is also small. This permitted us to interview all of the critical staff in Ocean County, including the only two caseworkers, and single vocational rehabilitation counselor. A second characteristic of the county is that a high percentage of adults with disabilities there have family members (especially parents) who both live in the county and maintain an active involvement with each other. Midvalley County is somewhat more populous (by Oregon's standards), with about 70,000 people. However, about two-thirds of this number live in one city in the county. The county has a mixed economic base of agriculture, lumber, and academic research. The county has a broader range of programs and services than Ocean County. It also has a reputation for developing innovative programs and emphasizing responsive case management. We were also attracted by the presence of a strong parent advocacy organization.

Angles of Influence: Case Study Findings about Perceived Patterns of Relationship

A research organization in our state that has a healthy sense of humor about itself made up T-Shirts for its staff a few years ago. Below the name of their organization, the T-shirts had the following motto in bold letters: "WE PROVE WHAT OTHERS ALREADY KNOW." We thought of this humbling slogan when, early on in our case study, we "discovered" something that seems incredibly obvious to us now. Our discovery was that any conceptual or schematic attempt to describe the relationship between a specific professional and a specific parent (or other family member) was incomplete without incorporating the status and location of the individual with the disability within that relationship. Instead of studying the relationship *between* the professional and the parent, we were really studying the relationships *among* the professional, the parent, and the adult. Our "discovery" of what the parents, professionals, and adults knew about the intricacies of their relationships led us to think of these relationships as a triangle. Tensions in the triangle arise over how the person with

the disability is perceived in terms of the adult role, and the nature of the assistance and support needed to maintain that role.

A second important feature of our findings is not so much a discovery of the obvious, as a reminder of a central tenet of interpretive research such as this. From this orientation, it is crucial to remember that relationships are social constructions based in large part on the perceptions of the people involved in those relationships. Any two people involved in a relationship can perceive it differently, and the point of interpretive case studies is not to decide whose perception is more "accurate." Rather, the point is to understand as fully as possible the various meanings or interpretations constructed out of those perceptions.

Dimensions of the Relationship

Figure 1 presents a basic equilateral triangle with each of the three angles representing one of the three people involved in multiple relationships among family, professional, and adult. Now, imagine that this triangle can be mapped along two variable dimensions. One dimension connecting the individual with the severe disability to the professionals and family members involved in his or her life connotes perceptions of adult status or personal autonomy. This "status-line" can run from one extreme of total dependence to another extreme of total independence. The second dimension connects the professionals and the family members together and refers to the perceived balance of influence or contribution each makes in providing support, guidance, and control of the individual with severe disabilities. This "influence line" can run from one extreme of professional dominance to the other extreme of family dominance. The triangle in Figure 1 reflects an idealized balance of appropriate influence and independence within the perceived relationships of the professional, family member, and adult. This balance serves as a foundation that maximizes the individual's adult status in the eyes of all the members of the triangle as well as others in the community.

In the course of doing our case studies, we never came across a situation in which all three parties to a relationship pattern would have the drawn the triangle depicted in Figure 1 to characterize their perceptions of the relational pattern. Triangles became distorted or changed along one dimension or another. Indeed, in most cases, the descriptions given by the various participants in the case studies suggest that people involved in the same relationship would have drawn triangles that looked very different from each other. That is, parents, professionals, and (where discernible) adults with disabilities perceive their relationships with each other very differently. However, three patterns of variation did emerge from our data. We have labelled these three patterns: (1) Flattened Triangles; (2) Forgotten Triangles; and (3) Incomplete Triangles.

Flattened Triangles

Our case studies have revealed a tendency for professionals to describe a pattern of relationship in which family members are believed to have too much influence and control in the lives of their disabled adult children. Professional influence and control is overshadowed by family influence making professionals feel more "distant" from the disabled adult. This "undue" family influence also diminishes the adult status of the person resulting in a relationship triangle that is skewed. From the professionals' vantage point, the family "gets in the way" of professional efforts to support the adult. As a consequence, the person's adult status is compromised. The top triangle in Figure 2 represents this pattern.

Conversely, our conversations with family members often revealed a contrasting impression where professionals were believed to possess more influence and control over the lives and decisions of their adult children. Families, too, feel distanced, even estranged, from their relative, but also perceive a diminution of adult status for the dis-

Figure 1. The Relational Triangle

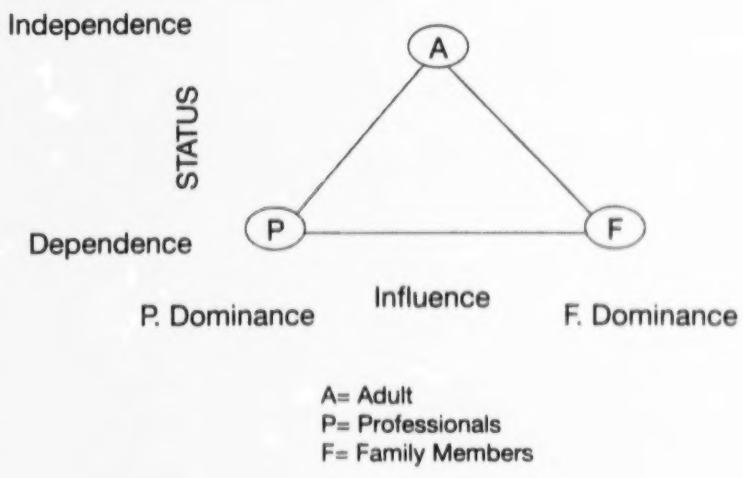


Figure 2. Flattened Triangle

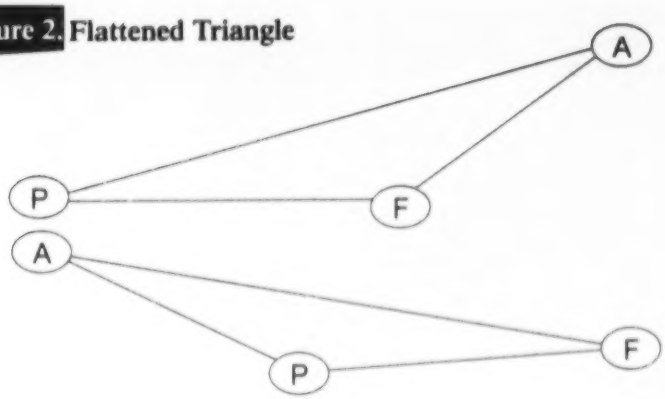
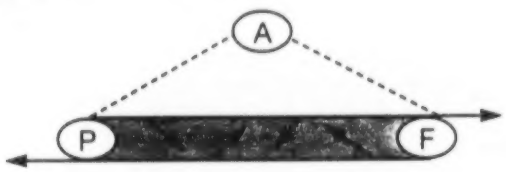


Figure 3. Forgotten Triangles



abled person. From these families' points of view, the professionals "get in the way" of their efforts to contribute to their relative's experiences of adult life. The bottom triangle in Figure 2 represents this pattern.

Forgotten Triangles

Of course, these differing perceptions of the shape of the relationship are not static. A family's perception of their relationships with professionals is likely to vary from person to person, as well as over time. Similarly, professionals' description of the triangle with any particular family may well vary from one interaction to the next. Finally, the perceived discrepancy between the professionals' triangle description and family members' triangle descriptions tend to vary in the same ways.

One way to explain these discrepant perspectives of adult status and influence is that the professionals and family members do not share a similar way of thinking about the meaning of adulthood for persons with significant disabilities. Professionals tend to assess adult status for any particular individual by thinking first about the most generic symbols of adults (chronological age, permission to make decisions, physical separation from parents, having a job, driving a car, etc.) and then determining the discrepancy between the individual and these more general social standards. The type and amount of professional support and assistance is then geared to helping the disabled adult acquire the skills and judgments that gradually and consistently reduce the discrepancy, resulting in ever increasing adult status. Given this perspective and approach, a family's most important contribution is to gradually reduce its involvement, leaving the young adult free to use his/her ever increasing repertoire of adult abilities.

Family members, on the other hand, are more likely to begin discussing adulthood in terms of the adult's ability to make self-preserving decisions of all types, rather than thinking first about broader social symbols or standards associated with adulthood. The range of decision includes major decisions about lifestyle, living arrangements, and financial matters, as well as self-preserving decisions about diet, management of home and possessions, relationships, and health and fitness. Consequently, families tend to begin their thinking about the assistance and support a person needs by thinking about the individual's abilities, limitations, history, and other personal attributes. Families are uniquely privy to this rich store of information whereas professionals only gain access, if they ever do, through the ability and willingness of family members to share the information.

Sometimes, for a variety of reasons, family members do not possess this archive of knowledge. Nevertheless, their way of thinking about their relative as an adult is still more likely to begin with what they do know about the individual than with symbols and standards. Whereas professionals seem to use a logic of deduction, families use a logic of induction.

One effect of families' and professionals' differing ways of thinking about the meaning of adulthood for persons with significant disabilities and how to support that adult experience, is that more often than not professionals and family members end up using the same language to misunderstand each other. Repeated misunderstandings have the additional effect of focusing the professionals and family members on each other, causing both to lose sight of the third member of the triangle. In effect, the relationships become dyads instead of triangles. Figure 3 tries to illustrate this process whereby the family and the professional overlook the status of the adult who is the

reason for their relationship in the first place.

Some Concluding Remarks

In reality, of course, most adults with significant disabilities have many different professionals in their lives, often substantially outnumbering their family members. Each of these professionals may well represent a different pattern of relationships with the adult and his or her family. In some cases, these multiple relationships occurred among our participants and seemed to create stress and confusion for both the adult and family members, leaving both uncertain about everyone's roles. Over the course of our study, managing this proliferation of relationships led some families to succumb to the power of the professional point of view.

Ultimately, it is important to remember that our triangles are only metaphors that we use to describe the various relationships that we discovered among parents, professionals, and adults with significant disabilities. We chose them to convey the strong sense of shape and structure that emerged from our conversations and observations. However, we also chose the triangle to convey two additional points. First, perhaps one key to improving family-professional relationships is to provide the participants with a convenient, visual way to summarize the multiple perspectives from which a relationship may be construed. Second, regardless of how the relationship between family and professional is drawn, the very occasion and goal of any relationship at all requires the third corner of the triangle not be overlooked. This third corner, at the top of the triangle, must always be the person with the disability. ♦

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Training Part H Early Intervention Practitioners *to Work Effectively with Families*

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Family Enablement Project
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Public Law 99–457, the Individuals with Disabilities Education Act (formerly the Education of the Handicapped Act), added a new program in 1986, Part H, designed to encourage states to establish comprehensive systems of early intervention services for infants and toddlers and their families. This federal statute has been heralded for significantly advancing special education policy, of which perhaps the greatest advance has been the central role afforded families in all aspects of planning and implementation of services. *"It is clear, both from the statute and the legislative history of the Act, that the Congress intended for families to play an active, collaborative role in the planning and provision of early intervention services"* (Federal Register, June 22, 1989, p. 26309). The word "families" appears many times through-

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out the statute, reflecting the obvious intended respect for the needs of families of young children with developmental disabilities. Congress derived the intent, spirit, and language of the Law from research in child development and early childhood education as well as from the practical experiences of both families and practitioners involved in existing early intervention programs. While embracing the sometimes unfamiliar concepts of "enhancing the capacity of families" (Sec. 671(a)(4), developing an "individualized family service plan" (Sec. 677), and providing "a statement of the family's resources, priorities, and concerns." (Sec. 677(d)(2)), federal and state planners and policy makers were quick to recognize that training early intervention personnel appeared to be critical to the ultimate success of PL 99–457. It has been noted by one authority that early childhood professionals need expertise and essential skills "related to working with the child in the context of the family, assessing family strengths and needs, communicating effectively with parents in order to identify goals of importance to them, providing family services, and acting as case managers" (Bailey, 1989, p. 107).

In 1988, the Early Education Program for Children with Disabilities (formerly the Handicapped Children's Early Education Program), Office of Special Education and Rehabilitative Services funded the Family Enablement Project specifically to provide assistance to states and early intervention programs within states as a part of their implementation of the P.L. 99–457 Part H Program. This outreach project provides training and technical assistance which enhances the capabilities of early intervention professionals to: (1) identify the needs and strengths of infants and toddlers with disabilties and their families, (2) promote families' competencies with respect to mobilization of resources to meet their needs, and (3) intervene to enable and empower families in ways that strengthen child and parent functioning.

As a result of the first three funded years of this outreach project, extensive training and technical assistance was provided in all 50 states and jurisdictions. More specifically, early intervention programs within 20 states participated in model adoption (replication) training. Additionally, workshops and conference presentations were made in 42 states/jurisdictions, with more than 2,000 persons receiving training.

Photo provided by Family Enablement Project

A Family-Centered Model

Recognizing that early intervention practitioners are increasingly being asked to function as "family specialists" in their work with children with disabilites or who are at risk for disabilites, the Family Enablement Project provides a model for employing a broader-based, family systems approach to early intervention. The model was developed specifically for professionals who have not had extensive training in family systems assessment and intervention practices. Based on seven model demonstration projects funded by the U.S. Departments of Education and Health and Human Services, the model takes very complex material regarding social and family systems theory and reduces it to a set of four substantive principles (see e.g., Deal, Dunst & Trivette, 1989). From these principles derive a process that is used to meet the needs of families in a way that increases the likelihood that

interventions will have positive effects on child, parent, and family functioning. Each principle has a number of operatives which collectively represent a framework and set of guidelines for promoting a family's ability to identify their needs and to mobilize resources in a way that strengthens family functioning (Dunst, Trivette, & Deal, 1988).

Family needs and aspirations, family strengths and capabilities (family functioning style), and social support and resources are viewed as separate but interdependent parts of the assessment and intervention process. The help-giving behaviors used by professionals are viewed as the ways in which families are enabled and empowered to acquire and use competencies necessary to procure support and mobilize resources for meeting needs (Dunst & Trivette, 1989).

The operationalization of the process may be described as follows: Family needs and aspirations are first identified to determine what a family considers important. Second, the unique ways in which the family system operates are identified to determine how the family typically copes with anticipated and unanticipated life events, and what aspects of the family system are functioning well. Third, the family's personal social network is "mapped" onto needs to identify existing and potential sources of aid and assistance that may be procured and mobilized to achieve desires and aspirations. Fourth, the optimal alignment and integration of the three parts of the family system occur, in part, by the help-giving behaviors (professional roles) that are employed as part of the assessment and intervention process (Dunst, et al, 1988). This family-centered assessment and intervention model is best described as a dynamic, fluid process that is continually operationalized each and every time the help-giver (practitioner) interacts with the family. Mastering the necessary material and practicing and refining skills needed to work effectively with families provides early intervention practitioners with a set of principles and competencies that permits them to promote a family's ability to mobilize support and resources to meet needs and attain aspirations in a way that is both enabling and empowering.

Effectiveness of the Training Efforts

A review of current personnel training studies reveals that training methods used in the field of special education have not been well researched (McCollum & McCartan, 1988). Evidence regarding the most effective techniques for designing and conducting adult learning experiences comes from the staff development literature (Showers, Joyce & Bennett, 1987; Sparks, 1983; Wade, 1984/1985). These adult learning studies indicate that the traditional "one-shot" training activities, usually in the form of a workshop, are generally ineffective in producing significant change in participants' skills or abilities. This research informs us that more preferable design allows training events or learning experiences to be spaced over a period of time, so that trainees have an opportunity to practice and refine newly acquired skills. The Family Enablement Project offers a variety of training and technical assistance activities ranging from dissemination of written materials about the family-centered model to conference and workshop presentations to intensive model adoption (replication) training. Materials, presentations, and workshops typically provide one-time, short duration contacts with participants, and focus primarily on awareness and increased knowledge of key concepts of the family-centered model. Model adoption (replication) training provides program staff with a variety of opportunities for learning spaced over a period of one year. This latter type of training typically includes sharing written materials about the model, conducting an on-site training/consultation with program staff, a visit for several trainees to the project demonstration site, one or two follow-up on-site trainings/consultations, and on-going monthly contacts between project staff and training participants by telephone and mail for feedback/consultation. Model adoption emphasizes both knowledge acquisition and application and adaptation of the model in everyday "real-life" situations. The extent to which the Family Enablement Project activities influenced the beliefs and behaviors of the persons participating in various types of training and technical assistance was specifically assessed as part of the project's evaluation activities. The subjects were 596 persons participating in the different types of training offered by the project. A Six Between Group (Method of Training) quasi-experimental design was used to ascertain the differential effects of material dissemination, conference presentations, two types of workshop training, and two levels of model adoption (replication) training on improvements in the ability of the trainees to work effectively with families. The seven topic (training) areas assessed were: (1) family needs assessment, (2) family strengths, (3) mobilizing resources and support, (4) staff roles, (5) partnerships, (6) case management, and (7) Individualized Family Service Plans (IFSPs). Each topic was rated by the training participants on a five-point rating scale ranging from "have not at all improved your abilities" to "have improved your abilities very much." The scale specifically measured the participants' self-assessed changes as a function of type of training. A Family Enablment Project Evaluation Form was sent to persons participating in each of the above types of training approximately one to two months following completion of the training event.

A one-way analysis of variance indicated that the trainees' differentially assessed the influences the training had on their abilities to work effectively with families. Model adoption (replica-

tion) training was clearly superior as a method for influencing the trainees' assessment of the impact of the training efforts. Post hoc analyses showed that the two types of model adoption training differed significantly from the other four types of training, and that the four types of "one time" training produced relatively similar findings. These findings, to the best of our knowledge, are the first set of evidence documenting the benefits of multiple opportunities training relative to other methods of training in the early childhood special education field.

Photo provided by Family Enablement Project

Conclusion

Most administrators, program managers, and others responsible for ensuring quality early intervention services agree that the purpose of staff training is to provide learning opportunities to influence knowledge and skill acquisition in ways that enable transfer to direct practice with children and their families. Yet the growing demands upon staff time for serving greater numbers of children and families, providing service coordination, collaborating with other service providers, actively involving families in all levels of service delivery, and meeting other requirements in implementing P.L. 99–457 lure us into thinking that programs cannot afford the luxury of intensive, recurring training opportunities. Traditional approaches to training (e.g., one or two day workshops and conferences) have great appeal due to their efficiency in providing knowledge and information needed by professionals in the field in a relatively short period of time. While these and other types of "one-shot" training methods are of value as "sources of information," the results from the evaluation of the Family Enablement Project indicated that trainees' perceptions of "increased abilities" were more powerfully influenced by multiple training opportunities. If early intervention practitioners are to acquire the critical knowledge and skills necessary to master a family-centered approach to working effectively with different types of families, there must be a commitment to sustained, supportive training opportunities that includes elaboration and refinement of techniques. Building on and refining the competencies of these practitioners is the vital key to ensuring that the family centered intent of P.L. 99–457 is achieved. The Family Enablement Project reflects an effort to do this.

For more information about the Family Enablement Project or to receive the quarterly newsletter, contact the Family, Infant and Preschool Program, Western Carolina Center, 300 Enola Road, Morganton, N.C. 28655, 704/433–2877.

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Implementing Individualized Family Service Planning in Urban, Culturally Diverse Early Intervention Settings

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Photo by J. Brown/G. Simon

What is Individualized Family Service Planning?

P.L. 99–457, the Individuals with Disabilities Education Act, formerly the Education of the Handicapped Act, modified the requirements of P.L. 94–142, the Education For All Handicapped Children Act, in such a way as to create new services for children with disabilities between three and six years of age and new incentives for states to develop a comprehensive system of services for children birth to three years of age and their families. Specifically the law directed states "to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families" (Section 671(b)). This section of the law is referred to as Part H and includes:

1. services must be provided under public supervision;

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2. services must be provided at no cost, except where federal or state law allows;

3. services must meet the developmental needs of children across language, psychosocial, cognitive, self-help, and physical areas;

4. services must meet state as well as federal standards;

5. services must include family training and counseling speech pathology, occupational therapy, physical therapy, case management, medical evaluation and diagnosis, special education, and screening;

6. services must be provided by qualified personnel; and

7. services must be delivered in conformity with the goals and services outlined in the Individualized Family Service Plan (IFSP) (Trohanis, 1989).

No requirement of Part H has generated more discussion than the requirement that each child and family have an Individualized Family Service Plan (IFSP) in place. Developing the IFSP requires a family centered, family focused, family driven approach to service delivery. It obviates the requirement for the Individualized Educational Plan (IEP) which exists for preschool and school age children under Part B. The IFSP differs considerably in both spirit and intent from the IEP, which is solely child focused.

Two of the primary purposes seen by the developers of Part H were to "enhance the capacity of families to meet the needs of their infants and toddlers with handicaps" in addition to enhancing "the development of handicapped infants and toddlers and minimizing their potential for developmental delay." (Education of the Handicapped Act Amendments of 1986, Sec. 101(a)). As Johnson, McGonigel, and Kaufmann (1989) stated so clearly "the IFSP is a promise to children and **families**—a promise that their strengths will be recognized and built on, that their needs will be met in a way that is respectful of their beliefs and values, and that their hopes and aspirations will be encouraged and enabled (p.1)." Families would be truly equals in a partnership designed to maximize the development of the child and the functioning of the family (Vincent, 1985).

Translating Philosophy to Reality

Translating the spirit of Part H, as it relates to IFSP, into reality in early intervention programs all around the country is a major task. In the past five years, professionals and family members have realized that the task is to define the process that will underlie the implementation of IFSPs. IFSP is not a set of forms, but a process. The most important part of the process is the relationship that is developed between the family and the early intervention service provider. As one early intervention provider explained:

> *"As you begin this early intervention program, you will be asked to form a partnership with the professionals who will be working with your child and family. As with all good relationships, it takes time to build the trust, respect, and sharing that is the foundation of a successful partnership. To this end the Individualized Family Service Plan (IFSP) is not just paperwork or evaluations that must be done so that your child can be enrolled in a program, it is a partnership that will last the entire time your child and family are with the early intervention program"* (Parents as Partners Project, 1988, p.1).

Trohanis (1989), Johnson, McGonigel and Kaufmann (1989) and Turnbull, R. (1989) have all summarized the required components of an IFSP as follows:

- family concerns, priorities, and resources assessment, along with a summary statement of a family's unique resources and coping styles related to enhancing the development of the child;
- multidisciplinary child assessment along with a statement of a child's present level of functioning in psychosocial, cognitive, speech and language, and physical development;
- a statement of the major outcomes expected to be achieved for the child and the family;
- the criteria which will be used to evaluate whether the stated goals and objectives have been reached, along with a timeline for achieving goals and monitoring progress;
- a statement of the specific early intervention services to meet the identified and prioritized needs of the child and family as related to enhancing the child's development with the frequency, intensity, and method of service delivery;
- the expected dates for the initiation of services and their anticipated duration;
- when appropriate, a statement of medical and other services to which a child and family will be referred;
- the service coordinator/case manager from the most appropriate discipline who will be responsible for monitoring the ongoing process of delivering and evaluating services and coordinating with other agencies; and,
- the plans and steps which will be taken to prepare the child and family for transition to mandated public school funded services at three years of age, if such a referral is appropriate.

As can be seen by inspecting this list, the requirements of the IFSP process are extensive and require substantial training of existing early intervention program staffs as well as modifications in the preservice training of professionals from a wide variety of disciplines.

A review of preservice programs conducted by the North Carolina Research Institute on Personnel Preparation (Bailey, 1989) indicated that most training programs did not have an emphasis on infancy and had even less coursework devoted to a family focused approach to intervention. Whether the discipline surveyed was nursing, occupational therapy, speech and language therapy, special education, nutrition, medicine, social work, psychology, or physical therapy, the amount of academic coursework and practicum experience devoted to young children with risk factors or disabilities and their families was extremely limited, often encompassing less than twelve hours of coverage. Thus, there is a continuing need for inservice and continuing education activities in order to bring the skills of the early intervention practitioner into line with the stated requirements of P.L. 99–457 as it pertains to developing IFSPs in conjunction with the child's family.

Photo provided by L. Vincent

Families as Experts

Particularly as it relates to working with families who come from different cultures, speak different languages, and have different values than that of the early intervention professional, inservice training and monitoring is a necessity. The likelihood that early intervention professionals will be representative of diverse/minority cultures is **not** very high. The enrollment of ethnolinguistically diverse minority students in the departments or schools associated with the "helping professions" has been declining; the percentage of professional staff members who are from diverse or minority backgrounds is often less than five percent (Federal Bureau of Labor Statistics, 1987). Thus, in addition to learning about the requirements inherent in P.L. 99–457, early intervention program staffs often need to learn about different cultures and child rearing practices. Thus, training materials are needed that will help to ensure that the IFSP process is implemented as *respectfully* and *effectively* with ethnolinguistically diverse/minority families as possible.

One purpose of the model demonstration project operated through the SHARE Center for Excellence in Early Intervention, Division of Special Education, California State University-Los Angeles is the development of these materials in conjunction with families and early intervention programs and staff who serve ethnolinguistically diverse/minority children and families. While sequences of activities and steps have been proposed to help guide the development of IFSPs, the use of these procedures with many different types of families has not yet been documented. Thus, although we have been able to describe the process to be followed, we have not established the parameters of its successful use with real families in real early intervention projects.

Johnson, McGonigel and Kaufmann (1989), in summarizing the work of the expert team, presented ten principles which underlie the IFSP process:

1. infants and toddlers are uniquely dependent on families for their survival and nuturance. This dependence necessitates a family-centered approach to early intervention;

2. states and programs should define "family" in a way that reflects the diversity of family patterns and structures;

3. each family has its own structure, roles, values, beliefs, and coping styles, and respect for and acceptance of this diversity is the corner-stone of family-centered early intervention;

4. early intervention systems and strategies must reflect a respect for the racial, ethnic, and cultural diversity of families;

5. respect for family autonomy, independence, and decision making means that families must be able to choose the level and nature of their involvement with early intervention;

6. family/professional collaboration and partnerships are the keys to family-centered early intervention and to successful implementation of the IFSP process;

7. an enabling approach to working with families requires that professionals re-examine their traditional roles and practices and develop new practices when necessary—practices that

Photo by L. Vincent

promote mutual respect and partnerships;

8. early intervention services should be flexible, accessible, and responsive to family needs;

9. early intervention services should be provided according to the normalization principle—that is, families should have access to services in as normal a fashion and environment as possible and that promote the integration of the child and family within the community; and,

10. no one agency or discipline can meet the diverse and complex needs of infants and toddlers with special needs and their families, therefore, a team approach to planning and implementing the IFSP is necessary (p.6).

Families are capable and competent decision-makers. Professionals provide assistance and support to families, rather than directions and solutions. The idea of using a family systems perspective in developing early intervention services is not a new one. As early as 1981, Foster, Berger, and McLean wrote about rethinking parent involvement activities from the perspective of the family, not that of the early intervention service provider. This family-centered approach is essential in our model project as we implement the IFSP process with ethnolinguistically diverse/minority families and their infants and toddlers with special needs.

As Vincent and Salisbury (1988), Fradd, Figueroa and Correa (1989), Vincent, Salisbury, Strain, McCormick and Tessier (1990), and Hanson, Lynch and Wayman (1990) have indicated, the face of the American family is changing rapidly. The majority of children entering public schools by the year 2010 will be of minority status. This change has already taken place in California. As of the 1989–90 school year, the state's students are 48.8 percent Anglo, 31.4 percent Hispanic, 8.9 percent African American, 7.5 percent Asian, 2.2 percent Philipino, .5 percent Pacific Islander, and .8 percent American Indian or native Alaskan (Daily Breeze, 11/12/89). This cultural, racial, ethnic, and language diversity necessitates that professionals do not make assumptions about family structures or roles. Sensitivity to differences in values, priorities, and experiences is essential.

The approach to family service delivery must value family differences while working to empower the family. Overall, current wisdom and accepted practice in the field of early intervention is to use a family systems perspective to empower and strengthen families as they work to meet the needs of their infants and toddlers with special needs. Sensitivity to the impact of culture, language, and race is essential. Hanson, Lynch and Wayman (1990) pointed out that early intervention and cultural values interact in the following areas: views of children and childrearing, views of disability and its causation, views of change and intervention, views of medicine and healing, views of family and family roles, and language and communication styles.

One task in our model project is to examine processes, procedures, and forms which currently exist to plan, implement, and record the IFSP. Family members from diverse backgrounds have been hired as experts to assist and guide us in this process. We have seen that particularly the initial steps in the IFSP process must receive careful systematic attention. The development of rapport and a relationship with the family is dramatically affected by cultural experiences and expectations, including previous experiences with the early intervention service delivery system. In our community, the average family of a child with a disability who is between two and three years of age

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is working with five different agencies to meet the needs of the child and family. This necessitates many visits and contacts with multiple professionals. Often these visits are not coordinated and families are asked to provide the same information over and over again. Eligibility is not the same across agencies and families often find themselves denied services which they believe their children need. In our community, a survey conducted by the Los Angeles Early Intervention Project (a countywide project responsible for planning for the implementation of Part H), found that one third of parents were not able to obtain the services they believed their children need. The required identification of family concerns and priorities is often overlooked. Instead, families told us that agencies and professionals decided what was right for them and their children. Documenting the concerns and priorities of Hispanic families has been a major focus of the model project.

The model proposed for our project involved providing families with choices on how to participate in the family identification of concerns, priorities, and resources (CPR) as required by Part H. The CPR assessment model was based on the premise that families can identify their concerns, priorities, and resources using a variety of techniques, from structured interviews and questionnaires to story telling techniques. Families should be given the choice of method.

We have also seen the need to explore techniques that do not involve professionals as the center of the information gathering process. We are utilizing parents as experts in the area of identification of concerns, priorities, and transition planning. We also have come to realize the vital role that paraprofessionals play in the early intervention service delivery system. Often, the paraprofessional has built a strong relationship based on trust with the family. The IFSP process should recognize, respect, and capitalize on this relationship.

Finally, we are coming to accept the IFSP form as a valuable tool. While true that the purpose of the form is to record the process, it communicates a set of beliefs about families and systems based on how it is structured and implemented. We have a small group of parents, professionals, and paraprofessionals working on a culturally sensitive, family friendly form. Piloting and refining the form and the training package will be a major focus of our third year of the model project.

Summary

Overall, we have learned a great deal. We believe even more strongly in the need for family-centered early intervention services and in the ability of families to be decision makers in theirs and their children's lives. We see a strong need for family members to be in leadership roles in policy and program implementation. We see a continuing need for personnel training related to cultural diversity, particularly in the area of building relationships. We believe that families and paraprofessionals as well as professionals must be included as partners in these training efforts.

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Parents: The Critical Team Members

Patty McGill Smith, Director

National Parent Network on Disabilities

Photo provided by Family Enablement Project

The National Parent Network on Disabilities (NPND) was founded on the principle of "parent and family involvement."

Parent Involvement

Parents are placed in a primary role in the service delivery chain when a disability is identified early in their child's life. With the identification of a disability, parents must become: the major force to influence and shape the life of their child; the most reliable and trusted source of information, experience, and strength for their child; experts when it comes to finding the most appropriate services for their child; and the "glue" that links all of the services together.

Lifetime Force

Parents of children with disabilities are the emotional, intellectual, and ethical referent from which children begin to mold and shape their own view of themselves and the world around them. If the parent displays despair over a child's disability, the child is likely to view the disability with despair. If the parent views the disability realistically and finds ways to lessen its impact, so will the child. As the child ages into adulthood, he/she will continue to be aware of how his/her parents deal with each challenge facing their child with a disability. Parents of children with disabilities must assume an active role in seeing that their children are safe, happy, and fulfilled. They plan and hope anxiously for the time when their children can live independently. They must be there at the beginning, through the battles and, far too often, at the end. Parents often feel an obligation to handle all of the challenges presented by disability throughout the lives of their children. And parents of children with disabilities who cannot rise to the challenge of disability for life, feel themselves "failures" more intensely than do parents of nondisabled children. Neither the bonds they develop with their child, nor their sense of continuing responsibility for their child's welfare, disappear at any magical age of majority. Parents of children with disabilities must plan for the day when they can no longer provide for their child.

Keepers of the History

Over the life of a child with disabilities, mounds of information are generated by physicians, educators, therapists, psychologists, and others. Amid all of that information, and sometimes nowhere within it, reliable information about the child exists. Parents of children with disabilities are the repository of all of that information as well as the keepers of the more informal, but no less important, history. As the child ages and moves from one service

delivery to another or while the child is involved in multiple, simultaneous service delivery systems, the parents may be the only ones who understand the basis for decisions made in each service delivery situation.

Parents see their child in a wide variety of settings, moods, and interactions. They are able to understand subtle cues from their child that communicate how things are going. Better than anyone else, they understand the child's potential through their knowledge of past behaviors. In essence, parents are the repository of the child's entire life experience.

Like parents of nondisabled children, parents of children with disabilities provide strength when they help their children through hard times such as being the object of name calling, being left out of games, going through puberty and adolescence, all create intense pressures for children with disabilities. In addition, parents of children with disabilities have to support their children in dealing with problems their nondisabled peers never have to face, such as the cognitive and physical challenges of daily living.

The Experts

Parents of children with disabilities have a unique understanding of their child. Parents of a child with a disability often have a keen sense of what types of services their child needs and of the most effective methods of service delivery. In nearly any service setting the parent is the only person who has a truly comprehensive knowledge of the child. While this expertise has been formally recognized through such legislation as the Individuals with Disabilities Education Act (IDEA), parents still have a long way to go before their expertise is fully utilized by the professional community.

Lifetime Link

Parents of children with disabilities become the single common element in all of the services, activities, and life events that their child experiences. They are, in essence, the "glue" that holds it all together. As service systems change, parents provide the information, history, and comprehensive knowledge that allows for a smooth transition from one type of service to another. They keep the paperwork up to date, attend countless meetings, transport, entertain, and provide the most basic and sometimes the most sophisticated care. Parents provide the lifetime link in the service chain through which the child moves during his life.

NPND Update

In 1987, the National Parent Network on Disabilities (then known as the National Network of Parent Centers) did not have office space, did not communicate in any systematic way with its membership, and had no professional staff. Its existence was due only to the hard work, persistence, and vision of parent leaders across the country who were the Charter Members of the organization. Since that time, NPND has grown in membership, fiscal stability, programmatic excellence, and national legislative presence. In 1989, NPND brought on its first professional staff member and assumed its current name. With this new name and with new categories of membership, NPND has been striving to recognize and include the valuable contributions made to the well being of parents of children with disabilities by parent leaders and educators. Organizations such as the American Association of University Affiliated Programs (AAUAP), the Association for Persons with Severe Disabilities (TASH), and the Special Olympics became affiliated members of the Network. Most importantly, parents who were not being served by any other parent organization were welcomed as members. The motivation for this is simple: Parents grow stronger through contact and association with other parents. Just as we want our children to reap the rewards of being fully included in their community and schools, parents should be able to reap like benefits by being included in the national community of their peers.

A Nationally Recognized Service Provider

In 1989, NPND took on its first subcontract for the provision of research services in conjunction with the Center on Resource Management in Concord, New Hampshire. This marked the first time NPND had generated fiscal support, apart from membership dues, through the provision of services. NPND has gone on to establish itself as a credible provider of services at the national level, dealing with information and issues that impact on parents of children with disabilities. As the credibility of the Network has grown, programmatic partnerships with local Parent Training and Information Centers (PTIs) have developed to provide valuable assistance to parents. Currently, the largest NPND project is a national outreach effort to help parents access Supplemental Security Income (SSI) benefits for their children. In addition to a national outreach strategy implemented through articles that appeared in *Exceptional Parent* magazine, three local or state level PTIs were targeted as sites for local demonstration outreach projects. PTIs in Philadelphia; Topeka, Kansas; and St. Louis, Missouri received educational materials explaining the SSI program and staff attended seminars on developing outreach activities. These PTIs also received funds to offset the cost of a part-time staff member to coordinate the SSI outreach activities at each site. Credible service delivery at the national level helps to combat the stereotype of parents as professionally inept and uninformed. This attitude has touched us all and is one force in establishing the credibility of the parent movement today.

Projects and services provided by NPND include:

- a NIDRR-funded research project under a subcontract with the Center on Resource Management in New Hampshire;
- supplemental Security Income (SSI) National Outreach to identify families of children eligible for SSI;
- management services for the Technical Assistance for Parents Projects, Boston, Massachusetts;
- a project for Strengthening Families in conjunction with the Human Services Research Institute in Boston, Mass.;
- SSI national outreach for Maternal and Child Health services in conjunction with the Institute on Child Health Policy, Gainesville, Florida; and
- staff support for the ADA Peer Training project operated by the New Hampshire Parent Information Center.

Legislative Activities

NPND has, as an activity central to its mission, represented the interests of parents of children with disabilities with one voice. Activities that have helped parents be heard nationally include:

- establishing a separate line item in the Individuals with Disabilities Education Act (IDEA) for Parent Training and Information Centers (PTIs);
- increasing funding for Parent Training and Information Centers;
- assisting with the passage of the Americans with Disabilities Act (ADA); and
- the addition of Parent Training and Information support for parents in the reauthorization of P.L. 99–457.

Through its membership in the Consortium for Citizens with Disabilities (CCD), NPND joined with 75 other disability advocacy organizations to fight for the passage of the ADA and other legislation supportive of parents and their families. The ADA is a major step in assuring Americans with disabilities access to work places, public facilities, and programs in all communities across the country.

Working in conjunction with its CCD partners, NPND has established the presence of parents and family members in the CCD proposed revisions of the Vocational Rehabilitation Act. Although this process has just gotten under way, the recommendations of CCD will gain serious attention as the process continues. Finally, NPND continues to work with other disability advocates to establish legislative initiatives in the areas of personal assistance services, family support legislation, and national health insurance reform.

AMERICA 2000

NPND has contributed to the development of the Administration's AMERICA 2000 initiative. This initiative offers parents an opportunity to reshape American public education through the President's six national education goals. As this reform movement grows, NPND will continue to serve as a communication link to parents on AMERICA 2000 activities.

Information Dissemination Activities

NPND has attempted to improve communication with parents and parent organizations nationally by publishing, in conjunction with Exceptional Parent magazine, a quarterly newsletter entitled "Networking." "Networking" is disseminated to 50,000 parents and professionals around the country.

To further ensure that information reaches parents and parent organizations/coalitions, NPND has recently activated an electronic bulletin board on Maternal and Child Health (MCH) Net. This bulletin board contains a wide variety of time-sensitive information of interest to parents and can be accessed through Special Net.

Conclusions

Parents gain validation by being accepted as important, contributing members of the team. Sharing with their children in the success of experiences they helped to create empowers parents unlike anything else. One successful experience builds upon another, creating a positive foundation for future interactions between parents and professionals. In a mutually supportive working relationship everyone wins. Everyone is empowered to do his/her best to ensure that children with disabilities receive the most effective social, educational, and vocational opportunities. We hope that this decade ushers in a new era of parent/professional cooperation and collaboration.

Serving Minority Children Who Are Severely Emotionally Disturbed and Their Families: *The Need for Culturally Competent Systems of Care*

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Introduction

The basic problems of limited access, uneven quality of care, and maldistribution of basic resources, while important to the nation as a whole, are critical to people from minority backgrounds who suffer acutely from the effects of these systemic defects (Christmas, 1977). Moreover, people from minority backgrounds are disproportionately affected by such societal conditions as poverty, unemployment, geographic isolation, and institutionalized discrimination.

The resource-poor environment in which the socialization of many minority children takes place, does not, for the most part, reinforce the positive attributes of the children/adolescents from such environments. Indeed, there are some who believe that African Americans, for example, have no culture to guard or protect. There is a growing recognition, however, that the practice of denigrating the cultures and achievements of ethnic minority populations has a negative impact on their children. Conversely, parents of successful children emphasize ethnic pride, self-development, awareness of racial barriers, and egalitarian values (Harrison, 1990). This suggests that human service providers should be constantly vigilant in their efforts to provide culturally relevant services, especially those involving ethnic pride and self-development, for the ever growing culturally diverse populations that make up our nation. Indeed, by the year 2000, approximately 40 percent of the clients in service delivery systems will be minority group members. It seems logical, therefore, for us to begin developing and implementing culturally competent systems of care to improve services to children from minority backgrounds and their families.

It is important that service providers understand that the help-seeking and help-accepting behavior of ethnic minority group members may arise from value orientations that are often quite different from those of the majority culture. Without such an understanding, theories of treatment, prevention, and service delivery will continue to be imposed that are not necessarily congruent with the culture of the population receiving services. As such, these services will be less effective and may in fact be damaging to some minority children/families.

We already know that when specific programs are culturally relevant, services tend to show an increase in the rate of utilization. The reverse is also true, if services are not culturally relevant, then utilization is decreased. Yet despite this knowledge, minority children/families still have not benefited fully or equitably from those systems responsible for providing services consistent with need.

If the needs of children and families from minority backgrounds are to be effectively met, then culturally competent systems of care must be developed and implemented. This requires congruence between (1) policymakers, those who set the goals, determine the mission, make the rules and regulations; (2) administrators, those who establish the structures for delivery of services; (3) practitioners, those who actually deliver the services; and (4) consumers, those who utilize the services. If there is lack of congruence with any of these four functions or levels, the effectiveness of the system or service is diminished (Isaacs, 1990).

The Child and Adolescent Service System Program (CASSP) Minority Initiative

Although there is no "cookbook" for providing effective services to children from minority backgrounds and their families, we do know that effective service delivery requires that services be agreeable with the culture of the

population receiving services. With that in mind, the CASSP Minority Initiative Resource Committee[1] began exploring ways to assist states and communities in their efforts to provide effective services to minority group members within a cultural context. This is consistent with the major goal of CASSP (a National Institute of Mental Health initiative) which is to improve systems for service delivery to children and adolescents with, or at risk for, severe mental and emotional disorders and their families. This includes assuring that service system development takes place in a context that is responsive to the special needs of culturally diverse ethnic minority groups.

The Cultural Competence Approach to Serving Minority Children and Families

One of the major activities of the CASSP Minority Initiative Resource Committee has been the development and dissemination of a two-volume monograph series on culturally competent systems of care. Volume one entitled *Towards A Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* was written by Cross, Bazron, Isaacs & Dennis (1989). It provided a philosophical framework; identified principles for a culturally competent system of care; set forth a six-point continuum for assessing cultural competence; and contained practical ideas for improving services to children from minority backgrounds and their families. Although the monograph focused on children with mental health problems, it is felt that the principles and concepts identified are equally applicable to any program or system serving minority group members.

As defined by Cross et al, cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, an agency or among professionals, and enables that system, agency, or those professionals to work effectively in cross cultural situations. The word culture is used because it implies the integrated patterns of human behavior that include thoughts, communication, actions, beliefs, values, and institutions of a racial, ethnic, religious, or social group. The word competence is used because it implies having the capacity to function effectively within the context of cultural differences. There are five essential elements that contribute to a system's, institution's, or agency's ability to become more culturally competent. The culturally competent system of care (1) values diversity, (2) has the capacity for cultural self assessment, (3) has institutionalized cultural knowledge, (4) is conscious of the dynamics inherent when cultures interact, and (5) has developed adaptations to diversity. Cultural competence is developmental in nature and involves practices based on accurate perceptions of behavior, impartial policies, and unbiased attitudes.

In responding to cultural differences according to Cross, et al, there are at least six possibilities along a continuum that programs should consider in assessing their level of cultural competence. They are (1) cultural destructiveness, (2) cultural incapacity, (3) cultural blindness, (4) cultural pre-competence, (5) cultural competence, and (6) cultural proficiency. The most negative end of the scale is characterized by attitudes, policies, practices, and structures that are destructive to cultures and consequently to the individuals within the culture. The most positive end of the scale is cultural proficiency which is characterized by holding a culture in high esteem.

Study of Program Examples

Isaacs and Benjamin, in a nationwide study of programs that utilize culturally competent principles in providing services to minority youth and their families, found that there are a number of dominant characteristics that these programs have in common. These programs, while developmental in nature, were unique in many ways in that each has chosen to operationalize one or more principles of a culturally competent system of care, while at the same time addressing the specific needs of the population served. Although there were 83 programs involved in the nationwide study, which spanned every region of the country, only 11 programs were selected for site visits based upon specific criteria. The remaining 72 programs participated in an extensive structured telephone interview process.

Most of the following principles and values of a culturally competent system of care were utilized by the programs participating in the study.

- The family as defined by each culture is the primary system of support and preferred intervention.
- The system must recognize that minority populations have to be at least bicultural and that this status creates a unique set of mental health issues to which the system must be equipped to respond.
- Individuals and families make different choices based on cultural forces; these choices must be considered if services are to be helpful.
- Practice is driven in the system of care by culturally preferred choices, not by culturally blind or culturally free interventions.
- Inherent in cross-cultural interactions are dynamics that must be acknowledged, adjusted to, and accepted.
- The system must sanction and in some cases mandate the incorporation of cultural knowledge into practice and policymaking.

[1] The CASSP Minority Initiative Resource Committee is a 21 member multidisciplinary group of minority professionals who are experienced in program, policy and administration involving children and adolescents with special needs from culturally and racially diverse backgrounds.

- Cultural competence involves determining a client's cultural location in order to apply the helping principle of "starting where the client is" and includes understanding the client's level of acculturation and assimilation.
- Cultural competence involves working in conjunction with natural, informal support, and helping networks within the minority community, such as neighborhoods, churches, or spiritual leaders.
- Cultural competence extends the concept of self-determination to the community.
- Cultural competence seeks to match the needs and help-seeking behavior of the client population.
- An agency staffing pattern that reflects the makeup of the client population, adjusted for the degree of community need, helps ensure the delivery of effective services.
- Culturally competent services incorporate the concept of equal and non-discriminatory services, but they also go beyond that to include the concept of responsive services matched to the client population.

Some of the dominant characteristics of programs that exemplified culturally competent principles/values were: a clearly defined philosophy and policies (the more clearly articulated the program philosophy and policies based on cultural dynamics and inclusion, the more culturally competent the programs tended to be); a strong emphasis on the importance of family as defined by the culture; staffing patterns that reflect the ethnic makeup of the population served; an emphasis on training, education, and curriculum development to address cultural issues; case management functions that maintain linkages with child serving agencies; and a tendency on the part of these programs to rally against societal injustices or inequities that impact on the well-being of their clients and communities. Finally, most of the programs participating in the study recognized that their services had to be adapted to fit the needs of minority children, adolescents, and families within a cultural context. Some of the cultural competence strategies which these programs used in appropriately adapting services to meet needs included implementing programs in schools to reduce the stigma of mental health treatment; extensive use of community volunteers such as Big Brothers/Big Sisters; involving the natural support systems, which include ministers and others respected in the community; emphasizing culturally relevant toys, printed material, activities, and decor; respecting the extended family system; and providing home based services.

Conclusion

Since availability of appropriate services and utilization of those services by ethnic minority youth and their families are directly related to the supply of appropriate personnel to staff them, then services should be provided by those who demonstrate some degree of cultural competence. It should be noted that "Cultural Competence is based on valuing 'differences' and the belief that it is all right to be different. Neither systems, agencies, nor professionals start out being culturally competent. Like other types of competencies, cultural competence is developed over time through training, experience, guidance, and self-evaluation" (Isaacs & Benjamin, 1991).

Efforts to improve services to minority children and youth who are severely emotionally disturbed and their families are tied to our ability to understand, respect, and involve minority families and communities in every aspect of service delivery. It is important, therefore, to accept, seek, understand, and utilize those cultural values and factors that have provided strength and sustenance to ethnic minority groups over time and to incorporate them into treatment interventions and program designs (Isaacs & Benjamin, 1991).

Information about the Culturally Competent System of Care Approach to Service Delivery described in this article is available through the CASSP Technical Assistance Center, Georgetown University Child Development Center, 2233 Wisconsin Avenue, NW, Suite 215, Washington, DC 20007, (202) 338–1831.

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Continued from page 2

them and what they need. In my work at OSERS, I have established a mission to ensure that all individuals with disabilities realize their optimal potential, productivity, and participation in our society. Young children have so much potential. By making sure that young children with disabilities and their families receive the support and intervention that is needed, we have the best chance of helping them to reach their full potential. As children approach that important transitional time between high school and whatever is to follow, we must take care to have systems in place that will support them in making their own best decisions for life-long productivity and participation. We can do this only if there is a long standing commitment between parents, educators, and rehabilitation professionals to work together in partnership to make sure the necessary services are available. We need to be partners right from the start, and maintain and strengthen those partnerships as time goes by. This will help ensure that our young children become full fledged participating members of society; that familes are not isolated; and that adults with disabilities are empowered to exercise greater independence, self-determination, and control over decisions that affect their lives.

Our goal in OSERS is to establish a coordinated educational system of lifelong learning for persons with disabilities, taking the best that each program has to offer, and molding it into something new and valuable. To me, this is the essence of what partnerships can and should be doing to improve the quality of life for individuals with disabilities. ♦

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